



## **Response to the Northern Ireland Assembly Health Committee Call for Evidence on the Organ and Tissue Donation (Deemed Consent) Bill**

24 September 2021

### **Introduction**

At Kidney Care UK, the UK's leading patient support charity, we have pleasure in responding to the Health Committee's Call for Evidence on the Organ and Tissue Donation (Deemed Consent) Bill.

At the outset we wish to place on record our recognition of the broad support provided by Members across the Chamber for this Bill during the Second Reading on Monday 20 September. As was clearly highlighted during the debate, charities – including Kidney Care UK – have been long advocating for this legislation in Northern Ireland as a means of increasing organ donations.

As such we were delighted to join the Health Minister last July as he announced that he was minded to bring this Bill before the Assembly and fully support the implementation of an Opt-Out system as the best opportunity available to increase organ donations and to save lives!

In framing our response to the introduction and passage of this Bill we have actively and frequently engaged with people with chronic kidney disease, including those who receive dialysis, are awaiting a transplant or have already received one to gauge their views on the wider move to an Opt-Out system for Northern Ireland.

Organ Donation is one of the most selfless acts of kindness one human can do for another and as a charity supporting patients right across the country we can attest to the thousands of people who are alive today thanks to the decision to become an organ donor. This includes a number of us at Kidney Care UK.

The Covid-19 pandemic has been an especially difficult time for kidney patients who, even during pre-pandemic times, already faced the prospect of losing their precious gift to a deterioration in their health. With a baby diagnosed with Chronic Kidney Disease at birth likely to require three of four transplants in their lifetime it highlights the need for any and all steps to be taken to increase the number of organ donations.

As a charity we appreciated the opportunity of taking part in the Patient and Client Council facilitated Stakeholder Event with Committee Members on 15 September.

We are also proud to have former MLA Jo-Anne Dobson as our Northern Ireland Ambassador. As the Committee will be aware Jo-Anne first submitted a Deemed Consent Organ Donation Private Members Bill – 'The Human Transplantation Bill' to the Assembly back in 2015 and remains a tireless campaigner for this issue, as acknowledged by Members during the Second Reading.

In conclusion, we are clear that the Bill has the potential to transform lives by giving kidney patients the hope for a better future and a life transformed through a transplant.

### **Response**

In responding to the specifics of the Bill as submitted at First Reading we make the following comments:

*Clause 1: "Appropriate consent" to adult transplantation activities: Northern Ireland*

(1) We believe that **amending Section 3 of the Human Tissue Act 2004** so that it is deemed that a person will be a donor unless they have stated otherwise in life is the right thing to do. We support the proposed exclusions as they are in line with those already in place in other jurisdictions.

In itself however this is not the only step that must be taken to increase organ donations. It is essential to ensure that the **education and promotion** around the change fully, clearly and continuously informs the public of how the new law will affect them and of the steps they need to take in life to help others following their death. This promotion should continue over a number of years, not just for the immediate period before and after law change. In addition, training for healthcare staff should always include a section on organ donation.

Changing the law in relation to consent does not diminish the need for people to have that all-important conversation about Organ Donation with their family members. A **continuous and consistent message** is needed across Northern Ireland to inform the public of what the law change aims to achieve and what it means for people's rights under it. The change must be supported by the right capacity in the health service, which has been stretched by the Covid situation.

We also support the decision not to deem consent to have been given in cases where the transplantation is of **novel material** as this ensures consistency of approach in relation to Organ Donation across UK countries.

(4) It is also appropriate that the Department will specify **permitted material** in regulations and that these will be laid before and approved by The Assembly - this remains consistent with the approach taken in other jurisdictions.

(7) We believe that the Health (Miscellaneous Provisions) Act (Northern Ireland) 2016 (duty to promote transplantation) and its subsequent amendment by this Bill are absolutely critical. Robust engagement with the public is required in order to achieve the aims of this Bill, however we also believe that a similarly robust programme is required for **children and young adults** prior to their 18<sup>th</sup> birthday. It is important that young people are aware of the choices which lie before them in relation to Organ Donation – that is whether to opt-in, opt-out or default to having their consent deemed.

Ongoing work in England, Wales and Scotland should guide the way forward in relation to engagement with children and young people. Extensive use of social media to inform the next generation of adults of their responsibilities is crucial and a **schools programme** would also help promote knowledge of rights under the law as well as making children aware of how they have the potential to save lives through becoming an Organ Donor.

## **Commencement and short title**

We recognise that the 12 months following passage of the Bill are absolutely critical to its success in increasing the number of organ donations. We urge the Assembly to ensure that funds are made available to provide a robust public engagement programme and would encourage Members to look to Wales, Scotland and England for their experience. Furthermore the period before the law comes into place is a critical opportunity to engage the public and NHS staff in open conversations to aid understanding of the plans, what they mean, and how they would be enacted.

The considerable increase in consent following the introduction of the Soft Opt-Out law in Wales is a very strong result of the impact of the work they have done there.

**Health Service Staff training** around the law change is also absolutely crucial and we welcome the fact that the new Simulation Centre at Queen's University is working alongside NHS Blood and Transplant (NHSBT) to deliver innovative training programmes for health professionals centred around 'Approaching the families of potential organ donors.' Kidney Care UK is proud to have played our part in bringing this from concept to reality through our Northern Ireland Ambassador Jo-Anne Dobson.

## **Conclusion**

We are conscious that the introduction of an Opt-Out system in Northern Ireland is the crucial final piece in the jigsaw of legislative reforms of consent surrounding organ donation across the United Kingdom and indeed British Isles. We are struck by the strong positive response to organ donation and opt-out plans expressed in the recent Department of Health consultation on the matter.

It has the potential to save many lives and is a hugely positive step in reducing the number of people who die needlessly every day waiting on a transplant.

## **Fiona Loud**

Policy Director – Kidney Care UK

## **Oral Evidence**

As a charity we would appreciate the opportunity to provide oral evidence to the Health Committee.

## **About Kidney Care UK**

Kidney Care UK is the UK's leading kidney patient support charity, providing practical, financial and emotional assistance for kidney patients and their families throughout the UK. We believe that no-one should face kidney disease alone; find out more at [www.kidneycareuk.org](http://www.kidneycareuk.org) or call 01420 541424.